

Kent County Council

# Strategy for Adults with Autism in Kent

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**A five year strategy**

**Kent Autism Collaborative**

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## **Membership of the Kent Autism Collaborative**

The following organisations are represented on the Kent Autism Collaborative, and thank everyone for their contribution to the development of the Kent Adult Autism Strategy:

- National Autistic Society
- Advocacy for All
- Kent County Council Adult and Children's Services
- Kent County Council Public Health Department
- Kent and Medway NHS and Social Care Partnership Trust
- Kent Supported Employment
- NHS Swale and DGS NHS CCG
- NHS South Kent and Coastal NHS CCG
- The South East NHS Commissioning Support Unit
- The Tizard Centre, University of Kent
- National Probation Service

## Foreword

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# 1. Introduction

## Why do we need a strategy?

It is a requirement for all Local Authorities to have a strategy for adults with autism as set out in the National Autism Strategy, 'Fulfilling and Rewarding Lives' (2010) and to have a local plan in place. This strategy addresses the needs of adults with higher functioning autism (including people diagnosed with Asperger's syndrome) and young people in transition.

This strategy is designed to hold organisations to account and provide commitments from these organisations in regard to their actions when implementing this strategy. It is aimed at a wide audience from professionals, individuals with autism and their families and carers to whole communities and the general public. As such we have endeavoured to write it as simply as possible, but inevitably when trying to write to such a wide audience, it will have some terminology that some readers will be unfamiliar with.

Autism is a lifelong condition that affects a person's development in particular:

- difficulty with social communication
- difficulty with social interaction
- difficulty with social imagination, which includes restricted, repetitive pattern of behaviour, interests, or activities.

A fuller definition of autism follows (see page 8).

In addition to the statutory and moral responsibility to improve support and care for all people with autism there is also an economic argument for improving the support and care for all people with autism. A study led by the London School of Economics and Political Science (Buescher, A., 2014) estimates that autism costs the UK at least £32 billion per year in treatment, lost earnings, and care and support for children and adults with autism. This is far higher than for other conditions, for example: £12billion for cancer, £8billion for heart disease and £5billion for stroke. They estimated the cost of an autism spectrum disorder throughout a person's lifespan as £0.92 million for those without intellectual disability.

The National Audit Office (2009) found that if local services identified and supported just 4% of the total number of adults with autism the outlay would become cost neutral over time. If they did the same for just 8% it could save £67 million each year.

## **Local Developments**

Much has been achieved for adults with autism in Kent since 2010. Until 2011 there was no clear diagnostic pathway for adults with autism in the absence of a learning disability. In order to get a diagnostic assessment people had to travel to the Maudsley Hospital in London. The responsibility for diagnosis of autism lies with the NHS. A more comprehensive explanation of the responsibilities of Local Authorities and the NHS can be found in the statutory guidance of Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy (2015).

In 2011 a specialist Kent Autistic Spectrum Conditions Team was established, comprising a diagnostic service funded by NHS Clinical Commissioning Groups (CCGs) and a KCC social care assessment and care management team. Demand for the service has been very high and both NHS CCGs and KCC have had to commit additional resources to address this.

At the time the Kent Autistic Spectrum Conditions Team was established, it was identified that extra capacity was needed in the community and voluntary sector to provide support for people with autism. 'Speaking up Groups' providing peer support for people with Autism and Asperger's Syndrome were commissioned from Advocacy for All and are now established in all districts. Advocacy for All are a charity based in Sidcup and cover south east London and Kent. They provide people with learning disabilities and autism free, independent, private advocacy to make sure they have control in their lives.

In the longer term the NHS CCGs and KCC are working with other stakeholders to develop an integrated all-age, Kent and Medway, neurodevelopmental pathway, initially focussing on Autistic Spectrum Conditions and Attention Deficit Hyperactivity Disorder (ADHD). The pathway will provide seamless care from childhood to adulthood, be based on good practice; integrate psychological, social and medical assessment, provide early intervention and be supportive of both people with autism and their families and carers.

## **Development of the Strategy**

In late 2014 an autism partnership board was established - the Kent Autism Collaborative. It was recognised that, whilst Kent had taken action to develop new specialist services, an Autism Strategy had not yet been developed to set out a plan for service improvements and developments. Therefore one of the first activities the collaborative was tasked with was to develop a Kent Strategy for Adults with Autism which sets out a high level vision of how the county achieves the aim that:

*“all adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents”*

*(Fulfilling and Rewarding Lives, 2010).*

## **Scope**

This strategy primarily addresses the needs of adults with autism who do not have a co-occurring learning disability (including people diagnosed with Asperger’s Syndrome) who live within the boundaries or are the responsibility of Kent County Council. The needs of adults with autism who have a learning disability are addressed within the Integrated Learning Disability Commissioning Strategy.

Adults with learning disabilities and autism are currently supported within learning disability services; however it is not to say that the issues, recommendations and principles set out in this strategy do not apply to those with learning disabilities. Awareness of autism, inclusion and good practice in relation to support for people with autism should apply to all those on the autistic spectrum.

Although mainly focusing on those over 18 years old, issues related to young people in transition are also included. Children’s Services have completed a separate Strategy for Children with Autism.

Work is currently being undertaken to develop an All Age Neurodevelopmental Pathway and it is envisaged that an All Age Strategy, encompassing all those with autism, ADHD and other neurodevelopmental conditions will be developed in the future.



## Organisation

This strategy links closely to the Joint Needs Assessment for Autistic Spectrum Conditions produced by the Kent and Medway Public Health Observatory (ref). This strategy also links with other local and national strategies, policies and guidance which will be referenced throughout.

The strategy is organised in sections reflecting the national strategy. Each section follows the same format:

- The views of people with autism
- The current situation (as of February 2016)
- Future commitments and priorities,
- Best practice,
- Key messages
- Key strategic objectives.

The views of people with autism are incorporated throughout the document. These include 'I' statements which were identified when engaging with people with autism in developing the national guidance 'Think Autism'. I statements are statements of intent, based on engagement with people with autism, phrased in the first person to make them more personal. This Strategy Document also includes the views of local people.

The strategy will be underpinned by an action plan to ensure implementation of the strategic objectives. This action plan will detail actions to be carried out in order to achieve the high level objectives, and will include corresponding measures.

## 2. What is Autism?

Autism is a pervasive developmental spectrum condition, which means it is a lifelong condition that affects a person's development in particular areas and in varying degrees. Traditionally, there have been three core areas of difficulty that are shared by all people with autism – these are often referred to as the 'triad of impairments'. They are:

- difficulty with social communication
- difficulty with social interaction

- difficulty with social imagination, which can include a restricted, repetitive pattern of behaviour, interests, or activities.

In the recently published Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) the triad has been replaced by two core areas of difficulty:

- Social and communication difficulties
- Restricted, repetitive patterns of behaviour, interests, or activities and unusual response to sensory stimuli.

*“While all people with autism share certain difficulties, their condition will affect them in different ways. Some people with autism are able to live relatively independent lives but others may have accompanying learning disabilities and need a lifetime of specialist support. People with autism may also experience over- or under-sensitivity to sounds, touch, tastes, smells, light or colours”*

*(National Autistic Society website, 2015)*

As indicated in the quote above, the key issue to be aware of is the enormous variation in how these core difficulties are manifested and how they impact on the lives of individuals with autism. It is important to recognise that there are also differences in how the core areas of difficulty can manifest in men and in women.

One of the key ways autism impacts on individuals is through very high anxiety and stress levels, which arise for a number of reasons. One of the primary reasons is their inability to predict what will happen and how people might behave and thus their reliance on structure, routine and their insistence on sameness.

Autism is often accompanied by other conditions, including other neurodevelopmental conditions such as:

- Neuropsychological conditions (e.g. ADHD, dyspraxia, synaesthesia)
- Sensory processing difficulties
- Learning disabilities and difficulties
- Neurological disorders, seizure disorders
- Health problems (e.g. bowel, skin, allergies)
- Psychiatric disorders (e.g. anxiety, depression, bipolar disorder, Tourette’s Syndrome).

However it is also really important to acknowledge the strengths of people with autism – in particular their strengths in processing visual information, in systemising and working with logic, their ability to focus in repetitive tasks, to identify patterns, their desire for accuracy, precision and perfection and often good rote memory.

*“Some features [of autism] are important for success in the arts or sciences.”*

*(Hans Asperger)*

### **3. National Policy Context**

#### **The Autism Act, (2009)**

The Act required the Secretary of State to issue a strategy for meeting the needs of adults in England with autistic spectrum conditions by improving the provision of relevant services to such adults by local authorities, NHS bodies and NHS foundation trusts.

#### **Valuing People Now, (2009)**

The strategy for people with a learning disability recognised that people with autism are some of the most excluded people in society and that policy makers and service providers were not specifically addressing their needs.

Fulfilling and Rewarding Lives’, The Strategy for adults with autism in England (2010)

The first version of the national strategy outlines five quality outcomes:

1. Adults with autism achieve better health outcomes
2. Adults with autism are included and economically active
3. Adults with autism are living in accommodation that meets their needs
4. Adults with autism are benefiting from the personalisation agenda in health and social care, and can access personal budgets
5. Adults with autism are no longer managed inappropriately in the criminal justice system.

## **The Equality Act, (2010)**

Under the Act you are disabled if you have a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities, and this includes people with autism. It legally protects people from discrimination in the workplace and in wider society. It contains a public sector equality duty, which means that public bodies have to consider all individuals when carrying out their day-to-day work, shaping policy, delivering services and in relation to their own employees.

Under the public sector equality duty public authorities are now required, in carrying out their functions, to have due regard to the need to achieve the objectives set out under s149 of the Equality Act 2010. This includes advancing equality of opportunity between persons who share a relevant protected characteristic and persons who do not share it; and fostering good relations between persons who share a relevant protected characteristic and persons who do not share it.

## **Autism: recognition, referral, diagnosis and management of adults on the autistic spectrum (National Institute for Clinical Evidence, 2012)**

These guidelines recommended that all local authorities should establish a specialist community based multidisciplinary team. It was suggested that a range of professionals should be involved including clinical psychologists, social workers, psychiatrists, nurses and speech and language therapists.

## **Think Autism, - Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update (2014)**

This update of the 2010 strategy sets out 15 new priority areas and reaffirms the importance of the 5 areas for action identified in the strategy aimed at improving the lives of adults with autism. The 15 priorities are set out as 'I' statements focussing on those with autism being an equal part of their communities; getting the right support at the right time during their lifetime; people being able to develop their skills and independence and being able to work to the best of their ability.

## **The Care Act, (2014)**

The biggest reform in social care for 60 years came into force in April 2014 and means a change to the way people can plan and pay for their care and support. It

makes clear that local authorities must provide or arrange services that help prevent people developing needs for care and support or delay people deteriorating such that they would need ongoing care and support. There are also new statutory duties for local authorities to provide advocates to people who need them as part of the assessment and planning of services, and to provide services for eligible carers.

The Care Act also addresses the issue of transition from Children's to Adult Services. Under the Care Act local authorities are required to identify young people who are not receiving children's services but who are likely to have care and support needs as an adult. The Care Act statutory guidance specifically references young people with autism whose needs have been largely met within education services.

### **National Institute for Health and Care Excellence (NICE) - Quality Standards for Autism, (2014)**

NICE quality standards are a concise set of prioritised statements designed to drive measurable quality improvements within a particular area of health or care. They are derived from high-quality guidance, such as that from NICE or other sources accredited by NICE. The quality statements are:

- **Statement 1.** People with possible autism who are referred to an autism team for a diagnostic assessment have the diagnostic assessment started within 3 months of their referral
- **Statement 2.** People having a diagnostic assessment for autism are also assessed for coexisting physical health conditions and mental health problems
- **Statement 3.** People with autism have a personalised plan that is developed and implemented in a partnership between them and their family and carers (if appropriate) and the autism team
- **Statement 4.** People with autism are offered a named key worker to coordinate the care and support detailed in their personalised plan
- **Statement 5.** People with autism have a documented discussion with a member of the autism team about opportunities to take part in age-appropriate psychosocial interventions to help address the core features of autism
- **Statement 6.** People with autism are not prescribed medication to address the core features of autism

- **Statement 7.** People with autism who develop behaviour that challenges are assessed for possible triggers, including physical health conditions, mental health problems and environmental factors
- **Statement 8.** People with autism and behaviour that challenges are not offered antipsychotic medication for the behaviour unless it is being considered because psychosocial or other interventions are insufficient or cannot be delivered because of the severity of the behaviour.

### **Winterbourne View: Time for Change - Transforming the Commissioning of Services for People with Learning Disabilities and/or Autism (2014)**

The report makes recommendations for a national commissioning framework under which local commissioners would secure community-based support for people with learning disabilities and/or autism and includes the following recommendations:

- The Government should respond to ‘the Bradley Report Five Years On’ to ensure that people with learning disabilities and/or autism are better treated by the criminal justice system
- A ‘Life in the Community’ Social Investment Fund should be established to facilitate transitions out of inpatient settings and build capacity in community-based services. The Investment Fund, seeded with £30 million from NHS England and/or Government, could leverage some £200 million from other investors to make investment more easily accessible to expand community-based services
- Action on the recommendations above should be accompanied by improved collection and publication of performance data, and a monitoring framework at central and local level. Data on key indicators (such as admissions rates, length of stay, delayed transfers, number of beds by commissioning organisation) should be collected and published.

### **NHS Five Year Forward View (2014)**

There are a number of priorities set out in the five year plan with emphasis on preventing people becoming ill and developing long term conditions, the NHS becoming a better partner with voluntary organisations and local communities and the NHS taking steps to break down the barriers in how care is provided between

family doctors and hospitals, between physical and mental health and between health and social care.

### **The Children and Families Act (2014)**

Under this Act Local Authorities, NHS CCGs and NHS bodies and Foundation Trusts have certain duties, including duties relevant to children and young people with autism and their families. The Act introduced a major transformation of the way services for children and young people with special educational needs and/or disabilities (SEND) are delivered. Changes include: Replacing Statements of SEN with Education, Health & Care Plans (EHCP), Parents with an EHC Plan will have the right to a personal budget for their support and the act applies from birth to 25.

### **Statutory guidance for local authorities and NHS organisations to support implementation of the Adult Autism Strategy (2015)**

The guidance focuses on the areas that section two of the Autism Act 2009 (which concerns the guidance issued by the Secretary of State) requires to be addressed, in each case identifying what Local Authorities, Foundation Trusts and NHS bodies are already under a duty to do under legislation, what they are expected to do under other existing guidance, and what they should do under this guidance. Each year Local Authorities are asked to complete a self-assessment framework showing progress towards implementation.

This can be found at:

<https://autism-connect.org.uk/users/myarea>

### **Building the right Support (2015)**

Sets out a national plan to develop community services and close inpatient facilities for people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition.

## **4. Local Policy Context**

### **KCC Select Committee Report - Autistic Spectrum Disorder (2009)**

This report made 15 recommendations. Key recommendations included setting up a specialist autism service and ensuring person-centred planning and greater use of direct payments by people with autism.

Other recommendations included:

- A Joint Strategic Needs Assessment for adults in Kent to establish the most effective way of conducting a county-wide study investigating the prevalence and incidence of adults with ASD in need of support and not currently receiving service provision
- Finding effective way of determining service user satisfaction for those adults with autism living at home and currently receiving support
- A review of availability of specialist health services including: psychology, psychiatry and speech therapy for people with autism both during transition and into adulthood.

### **Facing the Challenge: Delivering Better Outcomes (2013), Kent County Council (KCC)**

This document sets out KCCs policy response to the financial challenge they face over the medium term, as income reduces due to reductions in Government funding, but spending demands from demographic and other uncontrollable pressures continue to increase. It places the customer at the heart of service delivery and aims to shape services around people and place, including around stages and ages of life.

### **KCC Commissioning Framework, (2014)**

This Framework sets out the principles by which KCC will commission in the future as it works towards becoming a commissioning authority focussing on outcome based commissioning. These principles include putting customers at the heart of commissioning, building community capacity and developing resilient local communities.

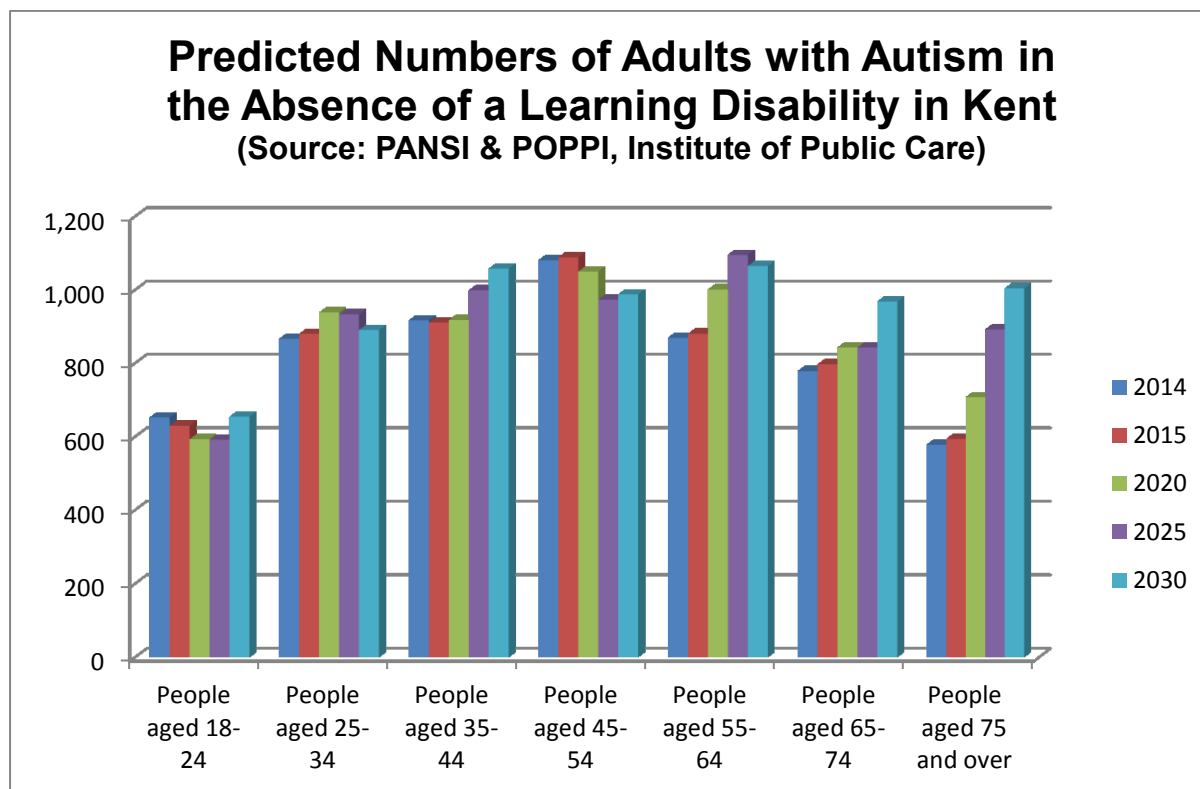
## **5. The Challenge – Prevalence and Needs**

It is thought that the overall prevalence of adults with autism nationally is 1.1% of the population<sup>1</sup>. With the Kent adult population (16 to 90+ years old) at the time of writing estimated at 1,221,000 then this would include approximately 13,431 people with autism. Current estimates suggest over half these will have a co-occurring learning disability and approximately 6,700 will have autism in the absence of a learning disability.



The Institute of Public Care produce projections for all adults and older people with autism until 2030. Assuming the number of people with autism in the absence of a learning disability is roughly half the total number, the numbers of adults with autism in the absence of a learning disability will rise overall by 15.4%:

<sup>1</sup>(Brugha T, et. al. 2012)



## Gender

Autism diagnosis rates are higher in males compared to females. The figure most often quoted is around 4:1. However an accurate estimate of the exact ratio is not available and estimates differ depending on whether people also have a learning disability. In addition autism spectrum disorders are under-diagnosed in females, and therefore the male to female ratio may be closer than is currently quoted.

## Co-morbidities

As noted earlier, autism rarely occurs in isolation and is frequently associated with other conditions such as ADHD, epilepsy, dyslexia and mental health issues.

Research by Baron-Cohen has estimated that almost 60% of people have a co-morbid condition. According to the National Autistic Society:

- 70% of people with autism have one co-existing condition and 50 % have two
- 70% have a learning difficulty, 50% have a learning disability

- 65% of people with Asperger's Syndrome have a psychiatric condition
- 84% of those with a Pervasive Developmental Disorder diagnosis have anxiety
- 30% have ADHD
- 10% have Obsessive Compulsive Disorder
- 25% have epilepsy.

In addition there are often other health issues including sleep problems which can exacerbate the difficulties faced by people with autism and which often go unrecognised or simply be attributed to the autism.

Finally, people with autism are sometimes seen to display challenging behaviour, which can be difficult for those who support them and which can significantly impact on their quality of life and that of their family and/or carers.

### **Challenges facing many people with autism**

- Being socially excluded due to the difficulty with social communication and maintaining relationships
- Difficulty in securing and /or maintaining employment
- Inconsistency in the response of services with people's needs 'falling between' services as autism does not always fit into traditional service silos such as mental health, physical disabilities and learning disabilities
- Risk of homelessness
- Risk of all forms of exploitation
- Being involved in the criminal justice system which does not understand their needs
- Increased physical health problems due to difficulties in engaging with health services or sensory sensitivities interfering with personal care.

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The condition and needs of more 'able' (higher functioning) adults with autism can often go unrecognised or misdiagnosed, leading to people being directed into inappropriate services and resulting in very poor outcomes for individuals. Adults with autism can live fulfilling and rewarding lives, but their autism and society's

response to them can present them with significant challenges at different times in their life.

## 6. The Collective Vision

We fully endorse the priority areas and vision for people with autism set out in the National Strategy for Adults with Autism in England and Wales.

*“All adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them”*

*(Fulfilling and Rewarding Lives, 2010).*

We want people to be accepted in their communities, to be able to access the right support, at the right time and to be able to be able to develop their full potential.

‘Think Autism’ (2015) contains fifteen ‘I’ statements grouped around three themes:

- Being an equal part of my local community
- Having the right support at the right time during my lifetime and
- Developing my skills and independence and working to the best of my ability.

This strategy and its accompanying action plan sets out how we will ensure these ‘I’ statements are being addressed in Kent.

At the core of this strategy is the desire to create an autism friendly society in its widest sense. We support the use of the National Autistic Society SPELL framework which comprises five core elements to be addressed to ensure autism friendly environments (see appendix one which contains a summary of the SPELL framework as developed by the NAS). SPELL stands for Structure, Positive (approaches and expectations), Empathy, Low arousal, Links.

## Core Principles Underpinning the Autism Strategy

- All adults with autism are treated equally and fairly and not discriminated against on the grounds of their condition, sexual orientation, gender identity, race, colour or religion
- Adults with autism are able to live their lives free from the risk of discrimination, hate crime and abuse
- People with autism have equal access to mainstream health and social care with reasonable adjustments made to achieve this
- The awareness of the condition and how to create autism friendly environments and provide autism friendly support is promoted and provided to all – encouraging communities to be “autism friendly”
- People with autism and their carers have the opportunity to express their views and opinions during the development of relevant services, guidance and policies and there is ongoing engagement
- A preventative approach underpins service development
- Services are flexible, based on individual needs and maximise choice and control for the person with autism and their families, carers.

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## 7. Leadership, Planning and Commissioning

Statutory guidance stresses the need for local authorities and NHS organisations to work together strategically to address the needs of people with autism. In Kent we have made some significant progress towards achieving this but we are committed to doing more.

We have identified a senior manager in Kent County Council to lead the commissioning of care and support services for adults with autism in Kent, known as the Autism lead.

We have established an Autism Collaborative which acts as an autism partnership board bringing together different organisations, services and stakeholders. The Autism Collaborative has developed this strategy and will evolve into an Autism Action Alliance to take the strategy forward.

In line with Best Practice the Autism Collaborative membership needs to be further extended to include people with autism and families and carers and key individuals from housing, employment and criminal justice.

An Autism Joint Needs Assessment has been developed which will be incorporated within the Kent Joint Strategic Needs Assessment. Some difficulty has been experienced in collating local data on autism and in future we need to improve our systems for data recording and monitoring. Statutory guidance also emphasises the importance of considering the needs of historically neglected (older people with autism) or hard to reach groups (black and minority ethnic groups).

A steering group made up of representatives from all Kent NHS CCGs and Kent County Council have been working together to develop an all age neuro developmental pathway for those with autistic spectrum conditions and ADHD. The Steering Group will continue to progress the implementation of the all age pathway.

We are committed to continuing to work collaboratively with our partners and across children's and adult services to help improve outcomes for people with autism. This will include improving opportunities for joint commissioning and supporting the development of services.

We will seek to develop the local market to better meet the needs of people with autism and ensure we adopt a preventative approach which maximises choice and personal control for people with autism and their families and carers.

Core Strategic Objectives		
	Objectives	Measures of Success
1	To work more collaboratively with our partners and across children's and adult services	We have developed services that work more closely together to support people with autism at all stages of their lives
2	To develop systems to routinely collect data on people with autism – numbers and needs	There is reliable local data system in place which informs the JSNA and the planning and commissioning of services
3	To extend the membership of the Autism Collaborative, and to develop the group into an Autism Action Alliance and implement the Action Plan	An Autism Action Alliance is in place and the Action Plan has been delivered

## 8. Engagement with People with Autism and their Carers

'I' Statements (Think Autism)
<p><i>(I statement No.2)</i></p> <ul style="list-style-type: none"> <li>“I want my views and aspirations to be taken into account when decisions are made in my local area. I want to know whether my local area is doing as well as others.”</li> </ul>
<p><i>(I statement No.8)</i></p> <ul style="list-style-type: none"> <li>“I want autism to be included in local strategic needs assessments so that person centred local health, care and support services, based on good information about local needs, is available for people with autism.”</li> </ul>

We are committed to involving people with autism in local decision making and the development of services and we have demonstrated this in a number of ways:

- During the development of the Kent Autism Spectrum Conditions Team carers and parents of people with autism were consulted and individuals with autism were included on the interview panel when the team were recruited

- A survey was carried out to solicit the views of people with autism and their families in the development of the all age Neurodevelopmental Pathway
- The peer support groups of people with autism, “Speaking Up Groups” which have been commissioned by KCC provide feedback quarterly to Commissioners and the specialist team. This feedback is given in written and video formats
- Consultation has been carried out on the annual autism self-assessment return which KCC are required to complete by Public Health England
- To inform the development of this strategy Advocacy for All was commissioned to seek the views of local people with autism on an initial draft document. Two engagement events were held, one in the East (Canterbury) and one in the West (Maidstone) and 45 people attended. A questionnaire was also devised which people could complete who chose not to attend the events.

We have included the views and experiences of the people consulted in the relevant sections of this strategy. A full report on the consultation is available in Appendix Two.

In the future we hope to involve people with autism and their families and carers on the Autism Collaborative and to develop more effective mechanisms for engagement. This Autism Strategy will be subject to a 3 month consultation period and an engagement plan will be developed and implemented to reach out widely to people.

We recognise we can do more to engage with people with autism and will seek to do this on a regular basis when we are designing or developing services.



## Best Practice

### The National Autistic Society Guide

The National Autistic Society has produced a guide for public authorities regarding involving people with autism in the planning and development of services and policies (NAS, undated). It acknowledges that:

*“There is no single preferred method of involvement for people with autism - it will depend on the preferences of each individual. There is a tendency for public bodies to use meetings as a mechanism for involving people. However, many people with autism find meetings difficult. Some people would be happy to use the telephone, while others may never use the telephone but might frequently use email. It is vital, therefore, to find out the communication preferences of the person in advance of their involvement.”*

The guide does however give suggestions as to how to meaningfully involve people and how to produce autism friendly documents.

The guide can be found at:

<http://www.autism.org.uk/~media/NAS/Documents/Working-with/Social-care/Involving%20people%20with%20autism.ashx>

## Best Practice

### Warwickshire County Council

In 2013 Warwickshire County Council consulted on their draft all age autism strategy using a number of different methodologies, to ensure they made the consultation as open and accessible as possible. Methods included:

- a dedicated Twitter account
- four focus group sessions with a variety of parent/carer groups across the county
- collaboration with the Warwickshire County Council consultation hub
- online and hard copy questionnaires
- a questionnaire designed for children and young people aged 16 and under, containing pictures and images
- a questionnaire for everyone 16 years and over, which was created in consultation with someone with Asperger syndrome.

## Engagement

- People with autistic spectrum conditions are frequently excluded from the planning and development of services and policies that affect them; this needs to change
- There is no single preferred method of involvement for people with autism - it will depend on the preferences of each individual.

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## Core Strategic Objectives

	Objectives	Measures of Success
4	To ensure people with autism and their families and carers are involved and have their opinions heard	Various mechanisms are in place and used when new policies, strategies and services are being developed and implemented. The views of people and their families are included in the evidence base for strategic decisions
5	To improve the understanding of Commissioners of the experience of people with autism (including the effectiveness of services and the outcomes achieved for individuals) This will include feedback from people with autism and their families and carers	Methods for collecting information on the experience of people with autism exist and this information used by Commissioners to improve the situation of people with autism

## 9. Diagnosis, Assessment and Support

### 'I' Statements (Think Autism)

*(I statement No. 7)*

- I want a timely diagnosis from a trained professional. I want relevant information and support throughout the diagnostic process.

*(I statement No. 10)*

- I want to know that my family can get help and support when they need it.

### Local People with Autism told us:

- It was the main area of concern and it was the area where the most negative personal experiences were reported
- Referrals to the Maudsley (Hospital) work well and their knowledge is excellent. Route to it could be easier though. It is very confusing for GP's to understand
- Adult referral for diagnosis should be a lot quicker and better funded
- Adapted cognitive behaviour therapy and sensory integration should be available to adults
- Post diagnostic support needs to be improved
- The support Kent provided through the Autistic Spectrum Conditions Team is advanced and cutting edge.

### Diagnosis and assessment

The statutory guidance makes it very clear that there should be a pathway developed for diagnosis, assessment, care and support for adults with autism in every local area. Also diagnosis of autism should act as a trigger for a needs assessment for the individual and a carer's assessment for the individual's family or carers. Guidance recommends the establishment of autism specific multidisciplinary teams; and for assessments to be started within three months of referral. (NICE guidelines, 2012).

At the current time (March 2016) Kent NHS CCGs are commissioning diagnostic assessments from two local organisations and there are significant waiting times.

Those with more complex issues or suspected ADHD co-morbidity are referred to the Maudsley Hospital in London.

A specialist social care service for people with autism is provided by the KCC Autism Spectrum Conditions Team in the Older People and Physical Disability Division. (OPPD). The team work with adults with autism who do not have a learning disability and accepts eligible young people through the transition process during their 17th year.

The team see people who have been newly diagnosed with autism but also accept referrals for individuals with 'strongly suspected' autism from a wide variety of sources. The team do not currently work long term with individuals with autism; those with eligible needs requiring ongoing support are transferred to the generic Area teams.

This team carries out a range of functions including assessment, short term interventions, support planning, personal budgets and information, advice and guidance for individuals with autism and their families/carers. The team also promotes awareness and provides information and advice to other professionals.

The service provided is based on the needs of the individual. Some people only need information and advice, some preventative services such as employment support, whilst others with eligible needs may require a support service.

The team has been piloting a new preventative approach to working with people with autism based on occupational therapy functional assessment and intensive skills training. This is proving very effective and helping people to become more independent.

The team is also evidencing how the provision of specialist assessment from professionals skilled in autism and a preventative approach can reduce crisis situations, improve outcomes for people and reduce the costs of expensive packages of care.

The work of the social care team has been hindered by the lack of access to multidisciplinary assessment and related skilled interventions (psychology, nursing, speech and language therapy), particularly for those with more complex needs.

The team has also experienced difficulties at times finding appropriate support services with an understanding of autism. We need to ensure that are enough diverse organisations operating in Kent to provide appropriate support for all people with autism.

For those with the greatest need (at the time of writing) there is no integrated specialist autism team in Kent including for example psychologists, speech and language therapists, and nurses who can provide multidisciplinary assessment and related skilled interventions. Access to services such as psychological therapies, forensic services, and positive behaviour support can also be difficult due to services being commissioned for other client groups or due to the limited knowledge and skills of some professionals and organisations in working with people with autism. This is a particular issue for those with an IQ around 70 who could be described as having a 'borderline' learning disability. Some individuals are referred back to the GP for onward referral to the Maudsley Hospital in London.

For those people with autistic spectrum conditions and concurrent acute or severe/enduring mental health problems, their mental health is managed through the appropriate primary or secondary mental health services and joint working takes place with the Kent Autism Spectrum Conditions Team. A new preventative Mental Health Social Work Service is also currently under development and we will ensure this team works closely with the autism team.

People with autism have high rates of co-morbidities. The Kent Autistic Spectrum Conditions team has found that between November 2013 and October 2014 of those who were referred 45% had mental health issues, 25% had ADHD and almost 33% had challenging behaviour.

The needs of some of these individuals can be described as complex and their behaviour can be risky to themselves and others.

Where people show severe challenging behaviour specialist services should provide assessment and treatment in the person's home as much as possible. If specialist challenging behaviour services are required then these should be developed locally and work within a positive behaviour support framework (Mansell, 1993 & 2007, Winterbourne View Report, DH, 2012).

The Local Authority and NHS CCGs in Kent are working together under the Transforming Care agenda to review current placements in inpatient settings and residential placements far from home and supporting people to move to more suitable places locally.

We are committed to improving our understanding of the needs of people with autism and complex needs or whose behaviour may challenge and to commissioning appropriate community services to meet their needs. We are also committed to community based support for people with autism that enables and empowers them through autism friendly environments and support to experience positive outcomes and thus reduce the demand for specialist challenging behaviour services.

### **ASC Peer Support Service**

At the time the Kent Autistic Spectrum Conditions Team was established it was acknowledged that there was a need for increased community capacity in the voluntary and community sector to support people with autism. In response to this a peer support service was commissioned and is run by Advocacy for All. The aim of the service is to:

- Develop and maintain peer support networks, social contacts and personal relationships
- Support people to live independent and fulfilling lives
- Optimise their physical and emotional wellbeing and manage anxiety associated with their condition.

### **Advocacy**

From 1st April 2016, all advocacy provision for adults in Kent will be managed via a single point of contact called Kent Advocacy. Kent Advocacy will be managed by SEAP (Support, Empower, Advocate and Promote), working in partnership with a range of other providers to deliver both statutory and non-statutory advocacy services in Kent. SEAP are experienced in working with people with autism.

This model of advocacy provision will ensure services are easy to find through a single point of access leading to improved efficiencies and better outcomes for vulnerable people. More importantly, this model will ensure that people are supported based on the need for advocacy, rather than client categorisation, although the partners in the delivery network will have specific qualifications and/ or

specialisms to ensure people are supported in a way that best meets their needs. The hub will also provide wider social value in the form of leadership on advocacy matters across the voluntary and community sector.

### **Future developments for diagnosis, assessment and support– the all age Neurodevelopmental Pathway.**

The Kent NHS CCGs have established an All Age Neurodevelopmental Pathway Project in response to the high demand for diagnosis, fragmented local services and commissioning gaps. This project has involved Commissioners from all the NHS CCGs, KCC representatives, family members, and other relevant stakeholders.

This project has led to the design of an all age health and social care neurodevelopmental pathway (See Appendix Three) which aims to improve diagnosis, assessment and support services. The pathway recognises the need to develop:

- Multidisciplinary assessment
- Post diagnostic support
- The provision of appropriate skilled interventions such as adapted Cognitive Behaviour Therapy
- A specialist consultancy and training role for mainstream services
- A positive behaviour management service.

At the time of writing the Kent CCGs have different plans to deliver the pathway within their areas; KCC has also committed additional resources to work on improving the pathway for children and adults with autism and aligning services with Health.

We need to maximise opportunities for joint commissioning and the integrated provision of services in the future.

## Best Practice

### **Bristol Autism Spectrum Service (BASS)**

The Bristol Autism Spectrum Service, provided by Avon and Wiltshire Mental Health Partnership NHS Trust is well-recognised across the country as a best practice model for diagnostic and post-diagnostic services. BASS is a multidisciplinary, specialist autism team jointly commissioned between health and social care. The team offer a diagnostic service, a comprehensive package of post diagnostic support including one to one sessions with specialist autism professionals and a range of groups (for example post diagnostic psycho-education, social skills/confidence, problem solving) They also offer supervision and training to professionals in mainstream services.

More information on the Bristol Autism Spectrum Service can be found at:  
<https://www.nice.org.uk/guidance/cg142/resources/the-bristol-autism-spectrum-service-bass2>

## Best Practice

### **Hertfordshire University Partnership NHS Foundation Trust Specialist Autism Team**

This Hertfordshire NHS Trust has a specialist autism team which also acts as a support network and training provider for mainstream services dealing with people with autism.

They additionally provide a good model of support to those referred. An advocate is allocated to each individual and they assist the client from referral through to post-diagnosis support. This helps facilitate and tailor the diagnostic process and ensure that it is adapted to the needs of the client. Advocates also assist after diagnosis with benefits, peer support and employment, as well as providing training in the SPELL framework.



## Diagnosis, Assessment and Support

There is a need to improve the response in Kent in the following areas:

- Multi-disciplinary diagnosis and assessment for those with suspected autism in the absence of a learning disability, including those with suspected co-existing ADHD
- post diagnostic support including related skilled professional interventions
- case consultancy to other health and social care teams
- support for people with challenging behaviour

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## Core Strategic Objectives

	Objectives	Measures of Success
6	To Address the current waiting list for diagnostic assessments	Health services in Kent are NICE compliant
7	<p>To implement the Neurodevelopmental Pathway to include:</p> <ul style="list-style-type: none"> <li>• Multidisciplinary diagnosis and assessment including those with complex needs</li> <li>• Post diagnostic support services</li> <li>• Provision of specialist interventions</li> <li>• Positive behaviour management service</li> <li>• Specialist information, advice and training service for mainstream professionals</li> </ul>	Pathway approved by all NHS CCGs and relevant KCC departments and all elements of the pathway operational

## 11. Facing Life Changes (Transition)

### 'I' Statements (Think Autism)

*(I statement No. 11)*

- I want services and commissioners to understand how my autism affects me differently through my life. I want to be supported through big life changes such as transition from school, getting older or when a person close to me dies.

### What Local People with Autism told us:

- There should be more specialist provision for young people in colleges
- Transitions need to cover a wide age range. People on the spectrum are emotionally immature and the skills of transitioning are dependent on emotional age. Therefore transitioning skills could be relevant when someone is 40, for example
- Much more flexibility is needed around transitioning. Teenagers in education will not, in all likelihood, be following neurotypical developmental patterns. They may not do their GCSE's until they are 18, for example. It is a learning disability, after all, even if their intellect is unaffected.

The Children and Families Act (2014) and the Special Educational Needs and Disability Code of Practice: 0 to 25 years (2015) apply equally to those with autism and their families as with other groups. This includes:

- Reviewing Education Health and Care plans annually. From at least Year 9, the annual review must include a consideration of the preparation for adulthood, including employment/higher education, independent living and participation in society. Transition planning must be built into the plan
- Focusing on progress towards the achievement of outcomes in an Education, Health and Care plan; and for those over 18 assessing whether the educational and training outcomes have been achieved

- Publish a “Local Offer” of educational, health, care and training provision available to these children and young people from their areas, including information about preparation for adulthood and independent living.

Under the Care Act (2014) Local Authorities are required to identify young people who are not receiving services but who are likely to have care and support needs as an adult. The Care Act statutory guidance specifically references young people with autism whose needs have largely been met by Education as an example of this.

We recognise that transitions to adulthood can be particularly difficult for young people on the autistic spectrum. The transition from childhood to adulthood can often involve a range of different changes, often all at the same time e.g. from school to college or work, out of the family home to living at university or in their own flat. It might also involve transitions associated with relationships – the ‘loss’ of school friends and the need to make new ones at university.

There is also recognition of the need to ensure that good transition processes are in place from Child and Adolescent Mental Health Services (CAMHS) to adult mental health services. Currently work is taking place to improve the provision of CAMHS services in Kent and this includes consideration of children and young people with autism.

KCC at the time of writing has been working to improve transition for disabled young people and has developed a new lifespan pathway model. (See Appendix Four)

A range of support is available to young people with autism from KCC. However services can appear fragmented and some young people are being seen by the Adult ASC team in crisis situation. It is recognised that more needs to be done to understand the experience of young people with autism and their families and improve services. As part of the all age Neurodevelopmental pathway work particular focus will be given to understanding the current situation for young people in transition.

### **Transitions throughout life**

Transitions do not stop in our early 20s but continue throughout our lives – meeting someone and getting married, having children, changing jobs, bereavement, transition to old age, etc. Times of change can be particularly difficult for people with

autism and for some additional support may be needed to help them deal with times of uncertainty and crisis.

## **Best Practice**

### **Autism research – University of York**

Research conducted by the University of York looked at the services most valued by young people with autism and particularly those with Asperger's Syndrome and higher functioning autism. These included:

- Help with facing and planning for adult life
- Specialist, and on-going employment support
- Peer support and opportunities to spend time with other with the same diagnosis
- Voluntary work placements in settings where autism was understood and accommodated.

## **Best Practice**

### **Greater Manchester Autism Consortium Transition Project**

This consortium undertook research into what was happening for people on the autistic spectrum during the transition from childhood to adulthood in Greater Manchester. The report made three recommendations:

- Better access to information for parents
- Better information about what adulthood means for young people
- Better understanding of needs from services within the community.

The project has developed workshop materials for parents and is developing resources to help young adults with autism prepare for adulthood.

## Transition

- Transitions can be a key time in the lives of people with autism as change can be problematic
- Education services need to refer young people with autism with care and support needs to adult social care
- The Care Act provides duties for local authorities to assess young people and child carers before they (or the person they care for) turn 18 in order to help them plan for transition to adult care and support (whether or not they have a service as a child)
- As for all other support, support during transitions needs to be autism friendly.

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### Core Strategic Objectives

	Objectives	Measures of Success
8	Develop and implement the Neurodevelopmental Pathway ensuring the needs of young people in transition are addressed	The all age Neurodevelopmental Pathway is working for those with autistic spectrum conditions and ADHD in transition
9	Ensure that there is sufficient good quality further education provision to meet the needs of young people across the autistic spectrum as close to the family home as possible	Young people are only receiving further education out of county by choice
10	Ensure a smooth transition from children's to adult services	Young people and their families /carers are satisfied with the transition

## 12. Training and Further Education

### 'I' Statements (Think Autism)

*(I statement No. 14)*

- I want the same opportunities as everyone else to enhance my skills, to be empowered by services and to be as independent as possible.

### Local People with Autism told us:

- There should be more courses relevant to people on the autistic spectrum and apprenticeships for people over 25
- There should be more courses that lead to paid employment with more practical and hands on training.

### The Vision for Children and Young People in Kent

Whilst 'I' statement 14 can be applied across all support provided, it is particularly important when considering educational support. The vision for the education of children and young people in Kent is set out in 'Working Together Improving Outcomes: Strategy for Children and Young People with Special Educational Needs and Disabilities' (KCC, 2013).

The vision is for a well-planned continuum of provision from birth to age 25 in Kent that meets the needs of children and young people with SEND<sup>4</sup> and their families. This means integrated services across education, health and social care which work closely with parents and carers and where individual needs are met without unnecessary bureaucracy or delay.

#### <sup>4</sup>Special Educational Needs and Disability (SEND) Strategy

It also means a strong commitment to early intervention and prevention providing early help in a timely way so that children's and young people's needs do not increase. It is expected that every early years provider, mainstream school and post 16 setting makes effective provision for disabled children and those with SEN that they make good progress in their learning and can move on easily to the next stage of their education and later into employment.

Although the specialist educational support described above is important, in order for young people with autism to be included as much as possible, schools and colleges need to be as autism-friendly as possible. As such, teachers and other staff (including administrative staff, canteen staff and playground supervisors) should have at least basic awareness training of how to support young people with autism. Individual approaches to learning and assessment, creative teaching techniques that take into account different learning styles and environments that are well structured and as low arousal as possible, will enhance learning for those with autism (and very likely for those without autism too).

### **KCC's Special Educational Needs Service**

KCCs Special Educational Needs (SEN) Service was responsible for ensuring the implementation of the Children and Families Act reforms of special educational needs which came into force in September 2014.

The Service commissions 4,000 specialist places in Kent maintained schools and academies, provision for 500 high needs students in further education and independent colleges and 400 independent and non-maintained sector placements. SEN contracts with help with health providers across Kent to ensure children and young people in schools have access to clinical therapies.

The service holds the lead role for delivering Kent's Special Educational Needs and Disability (SEND) Strategy, launched in January 2014. The overarching aims of the strategy are to:

- Improve the educational, health and emotional wellbeing outcomes for children and young people with SEND (including those with autism)
- Ensure KCC delivers statutory change required by the Children and Families Act 2014
- Address gaps in SEN provision; improve quality; encourage a mixed economy of provision.

A 'Local Offer' of educational, health, care and training provision available to children and young people in their areas has been published on Kent.gov. Further information is available through the former Parent Partnership Service which is now known as Information Advice and Support Service Kent (IASK). The role of IASK includes providing information, advice and support to children and young people with SEND

up to the age of 25, in addition to their parents. IASK has recruited an Independent Supporter for young people.

The SEN Service has ensured there is more secondary provision for pupils with autism and speech and language difficulties and have expanded existing good provision for speech and language to include autism places in primary schools.

## Best Practice

### Autism Education Trust

There are a number of examples of good practice of inclusion for young people with autism. The Autism Education Trust (<http://www.autismeducationtrust.org.uk/>) has developed some standards and competencies for those involved in educating young people with autism. There is also guidance for how local authorities can use the tools for teachers.

## Education

- Having a diagnosis of autism or Asperger syndrome needn't be a barrier to entering further or higher education
- More work needs to be done to help local authority schools and academies provide better services for people with autistic spectrum conditions so they can develop their skills and have control over their own lives.

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<b>Core Strategic Objectives</b>		
	<b>Objectives</b>	<b>Measures of Success</b>
11	To establish a clear transfer process for transition from school to college	Transfer process in place and people with autism, their families and schools report it is clear
12	Establish tracking of people subject to EHCPs above statutory school age to remain alert of those NEET and whose destinations are not known	Tracking mechanism in place
13	Commission outcomes for 0-25 Speech and Language Therapy	By September 2017, therapy services jointly commissioned by KCC and the CCGs will be underpinning good educational outcomes for children and young people with communication and interaction difficulties, developing a skilled workforce to support learning
14	Educational establishments provide autism friendly support and environments and promote positive outcomes	Young people and their families report positive experiences at school or college
15	Fewer young people drop out of college without qualifications	More people leaving college with qualifications

## 13. Employment

### 'I' Statements (Think Autism)

*(I statement No. 15)*

- I want support to get a job and support from my employer to help me keep it

### Local People with Autism told us:

- When asked for their top three concerns employment was second
- Kent Supported Employment is good at working with people with complex needs
- There is not enough support for people in work and support services do not have experience in finding work for highly qualified (i.e. post graduate) people on the spectrum
- Generally employers do not understand the needs of people with autism and people are vulnerable to bullying in the workplace
- Better information about what reasonable adjustments employers should be expected to make is needed.

It is widely recognised that adults with autism are heavily under-represented in employment with the National Autistic Society stating that only 15% of people with autism are in paid employment.

The Autism strategy 'Fulfilling and Rewarding Lives' (2010) and 'Think Autism' (2015) both include commitments aimed at increasing the number of adults with autism in work through the provision of guidance and training to employers and employment support services and ensuring adults with autism benefit from employment initiatives.

In Kent there are a number of ways people with autism may get help with employment.

There are Disability Employment Advisors at local job centres whose role is help people with disabilities find a job or gain new skills and identify disability friendly employers in the area.

Work Choice is a voluntary Department for Work and Pensions (DWP) employment programme which helps disabled people with more complex issues find work and stay in a job. It is available to people with substantial and long term conditions and provides support in preparing to get a job, with the recruitment process and longer-term in-work support.

KCC employ a number of individuals on the autistic spectrum and provide apprenticeships to people with autism. Although equalities data is not presented by disability type in June 2014 4.2% of the non-schools based staff classified themselves as disabled.

KCC commission Kent Supported Employment (KSE) to provide supported employment to people with a learning disability, physical disability, sensory disability and autism. They currently report that approximately half their caseload is people with autism. They work with individuals and potential employers to help them prepare for, find and maintain employment.

Kent Supported Employment is currently working with East Kent Further Education College and Queen Elizabeth and Queen Mary hospital to provide 12 week internships at the hospital. They are also working with four special schools in Kent to develop a similar scheme with local hotels.

There are other organisations in the community, voluntary and social enterprise sector in Kent that offer employment support to people with autism, such as the National Autistic Society and the Shaw Trust.

Whilst paid employment is very important, when people are not employed then it is important that they are supported to have meaningful occupation in other ways, for example, through: education (at college or at home), voluntary work, community activities including sport and leisure, household activities, hobbies etc. People may need help to identify and initially access such opportunities but quite often many of these can be sustained relatively easily over time by the individual themselves.

We also ensure that needs assessments, care plans and transition plans consider employment as an outcome and actively signpost individuals to sources of support.

We are committed to doing more to improve the employment prospects of local people with autism. There are a number of areas we need to address including:

- Understanding the employment needs of the local population of people with autism
- Understanding the barriers people face and how to overcome these
- Addressing the employment needs of young people leaving children's services
- Considering adjustments to our employment practices to increase the recruitment and retention of people with autism
- Considering developing Apprenticeship schemes and other employment support services
- Widening autism awareness training to employers and Job Centre Plus.

To this end we will invite representatives from Jobcentre Plus and local employers to join the Autism Collaborative and encourage them to attend and play a meaningful role in providing setting a clear steer for improvements in this area.

We will also establish a specific sub group of the Autism Collaborative to consider the areas outlined above and the actions that need to be taken to improve employment for people with autism in Kent.

## **Best Practice**

### **Case Study Surrey Employability**

Surrey Employability is a partnership project run under the auspices of the Jobcentre Plus, the National Autistic Society, and Employability (Surrey Choices Limited). The project selected adults with autism on the basis of their employment status and determination to find work. Fifteen individuals were chosen and invited to attend an Employability Support Employment training course for two days which provided job seeking methods, CV preparation, confidence building, interview tips and techniques, culminating in a mock interview for a specific job.

Some were work ready but some needed to gain confidence and were offered voluntary experience. The aim was for each individual to experience two work placements over the six months of the project. As a result five have found work and a further five have had work experience.

## Employment

- Adults with autism are heavily under-represented in employment
- People with autism want to work and have skills and talents that are useful in the workplace
- People working with adults with autism should start from a position of a 'presumption of employability'
- Other forms of meaningful occupation should also be valued and supported.

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## Core Strategic Objectives

	Objectives	Measures of Success
16	To provide a range of support to people with autism to increase the numbers of people with autism who are in employment – paid or voluntary	Increased numbers of people with autism in employment

## 14. Housing, Care and Support

### 'I' Statements (Think Autism)

*(I statement No. 3)*

- I want to know how to connect with other people. I want to be able to find local autism peer groups, family groups and low level support

*(I statement No. 5)*

- I want to be safe in my community and free from the risk of discrimination, hate crime and abuse

*(I statement No. 12)*

- I want people to recognise my autism and adapt the support they give me if I have additional needs such as a mental health problem, a learning disability or if I sometimes communicate through behaviours which others may find challenging.

*(I statement No. 14)*

*I want the same opportunities as everyone else to enhance my skills, to be empowered by services and to be as independent as possible.*

### Local People with Autism told us:

- We want the same opportunities as other vulnerable groups to appropriate housing and housing authorities should listen to what we need
- There should be different ways to access housing rather than having to go through the bidding system.

### Housing and Support for Independent Living

Local authorities have a statutory responsibility to consider the accommodation needs of people they are providing care and support to.

The Kent Social Care Accommodation Strategy – Better Homes: Greater Choice - specifically references people with autism. It acknowledges the key actions and

recommendations in the national autism strategy in regard to accommodation which are:

- Individuals are living in accommodation that meets their needs
- Improved access to the services and support people need to live independently within the community.

A range of accommodation options should be available in Kent for people with autism, based on their individual needs.

A range of options are also needed to provide support to people with autism requiring help to live independently, for example family or community networks, Personal Assistants, voluntary organisations, commercial providers, Supporting People (housing related) support services. As recommended in the Living in Fear project conducted in Kent and Medway, consideration of the support people need to live independently, should take into account their experiences of and vulnerability to hate crime and victimisation (Beadle-Brown, J. et. al., 2014).

There are other voluntary organisations that are not commissioned providing autism specific support across the county such as the Kent Autistic Trust, the National Autistic Society, Hendricks Associates and Ashford ASD. These organisations provide a range of services: advice and support, day services, parent and carer support, residential care, education, counselling and leisure facilities.

There are in addition, a number of commissioned and non-commissioned organisations that provide services that can be accessed by adults with autism, but which are not autism specific. Some of these services need to be improved by having greater awareness and understanding of autism to better meet the needs of this client group.

In Kent, commissioners have been working hard across health and social care to ensure that people living in hospitals and in specialist placements outside the county including those with autism can be accommodated safely in the community with appropriate support.

The Transforming Care Programme sets out suggested ways for improving the quality of care for people with learning disabilities and or autism. It suggests Local Authorities and NHS bodies and NHS Foundation Trusts Work together to put in

place a locally agreed joint plan to ensure high-quality care and support services for all people with challenging behaviour.

We are committed to improving our understanding of the accommodation and support needs of people with autism and ensuring the availability of appropriate housing and support services.

## **Care and Support – Adult Social Care**

The vision for Adult Social Care which is in development, sets out a number of objectives presented in the context of promoting wellbeing; promoting independence; supporting and maintaining independence. In summary, these are:

### **Promoting Wellbeing**

These services aim to prevent, delay or avoid people entering into formal social care or health systems, by enabling people to manage their own health and wellbeing. Wellbeing services are universal, based in local communities and utilise local resources. They address the issues that lead to people entering into formal care systems, such as social isolation, falls and carer breakdown. Access to good quality information and advice will be the cornerstone of our wellbeing offer, enabling people to identify and access the support that they want in order to keep living fulfilled lives.

Accessible information should be available for autistic adults about how they can access information about preventative services. These services should be autism friendly in line with this Strategy.

### **Promoting Independence**

These services also aim to prevent or delay people entering into formal care systems by providing short-term support that provides the best long-term outcome for an individual. For some people, these consist of short term interventions that enable people to recover from episodes of ill health or injury and to return to their previous level of health. For other people, especially those with a long term condition or a disability, these may be fixed term services that provide training and skills development that maximises independence and enables people to live as independently of formal care systems as possible. This is the level of Intervention where OT based enablement service, CBT, Positive Behavioural Support etc. is needed.



## Supporting and Maintaining Independence

Some people will need ongoing support to remain living in their own homes and communities. These services aim to maintain individual wellbeing and self-sufficiency, keep people safe and enable people to live and be treated with dignity, enabling people to live in their own homes, stay connected to their communities and avoid unnecessary admissions to hospitals or care homes.

People with autism should be able to access any of these levels of support depending on their needs.

For those with more intense support needs, achieving these outcomes requires those who provide support to have specific skills in enabling and empowering people to participate in all areas of life and in any decisions about their life. Those providing support need to be able to work with people with autism in an enabling and empowering way such as within the SPELL framework and “Active Support”.

### Best Practice

#### Active Support

Research over almost fifty years has shown that living in an ordinary home dispersed in the community is a necessary but not sufficient condition for better outcomes for people with disabilities. Once in the community, there are primarily two factors that determine the quality of life of people with disabilities (and in particular how involved they are in all aspects of their lives) - the severity of their disability (those who have higher levels of adaptive functioning, tend to experience better outcomes) and whether staff provide them with facilitative help to be engaged in meaningful activities and relationships. Mansell and Beadle-Brown (2012) describe this approach as “an enabling relationship”, the aim of which is to improve people’s quality of life and in particular to enable them to develop their skills and independence, to experience real choice and control over all aspects of their lives and to become a valued member of their community, irrespective of the severity of disability or the presence of additional issues or difficulties (such as autism or challenging behaviour). Although Active Support was originally designed to support those with severe learning disabilities as they moved from institutions into the community, the principles can be applied in many other situations. Recent research

(Beadle-Brown et. al., 2015) has also shown that active support is important for those with autism and when active support is in place, other elements of good support such as good support for communication, autism friendly practices and positive behaviour support are easier to implement. Active support is closely connected with Positive Behaviour Support and has been shown to result in the reduction in challenging behaviour as well as positive quality of life outcomes. However, research has also shown that less than 1/3 of people using services for people with learning disabilities receive consistently good active support – this is true for single person services as well as for larger residential services and for autism specific services as well as more generic learning disability services. United Response has been implementing active support for many years (being one of the first organisations to do so at a whole organisational level). Their website is a useful resource on active support (<http://www.unitedresponse.org.uk/active-support>) and includes materials on the relationships between Active Support and Positive Behaviour Support. (<http://www.unitedresponse.org.uk/transforming-care>).

## Housing, care and support

- Historically the housing care and support needs of people with autism have often been met through placement in accommodation designated for clients with a learning disability or mental health needs
- The needs of those with autism in relation to housing and support must be better understood
- Attention must be paid to this in developing local services for those with autism That are autism friendly, enabling and empowering in order to reduce the likelihood of challenging behaviour developing to reduce the need for specialist out of county placements.

Consideration needs to be given to workforce development and leadership – whether supporting people in their own home or in community-based accommodation and support services to ensure appropriate care, support and housing for people with

autism.8

<b>Core Strategic Objectives</b>		
	<b>Objectives</b>	<b>Measures of Success</b>
18	Undertake a housing needs assessment of people with autism	Housing needs report produced
19	Develop a diverse housing market that provides various levels of skilled support	There are housing options available to all people with autism
20	Work with the market to develop a range of housing related support services	All are able to access appropriate housing related support
21	Ensure social care, health and educational support services provide skilled, effective, autism friendly support, using an enabling and empowering approach	Reduction in the number of people with autism being placed out of area and in particular being sent to specialist challenging behaviour settings; reduced placement breakdown; reduction in number of people accessing mental health services; people report better experiences of social care, health and educational support
22	Develop specialist services that can provide assessment and treatment, ideally within individuals' current home or, where necessary, in small local specialist units implementing positive behaviour support and the SPELL framework	Fewer admissions to acute services. Reduction in number of out of area placements for people with autism who show behaviour that challenges. People return to their home or find a new one within six months of admission to specialist assessment and treatment services

## 15. Workforce Development

### 'I' Statements (Think Autism)

*(I statement No. 9)*

- I want staff in health and social care services to understand that I have autism and how this affects me

*(I statement No. 4)*

- I want the everyday services that I come into contact with to know how to make reasonable adjustments to include me and accept me as I am. I want the staff who work in them to be aware and accepting of autism

*(I statement No. 6)*

- I want to be seen as me and for my gender, sexual orientation and race to be taken into account.

### Local People with Autism told us:

- There is a lack of understanding of the condition amongst many professionals
- When asked for the top three concerns from all the key areas in the strategy the third most important was workforce development; 25% agreeing that training for employees who worked in public services was very much needed
- As the condition is an invisible disability people often perceive people's behaviour in a negative way
- Some staff assume all autistic people are the same
- When planning buildings etc. the needs of people with autism should be taken into account to produce 'autism friendly' environments.

The strategy and statutory guidance emphasise the critical importance of staff training; providing effective training should enable staff to identify, support and respond appropriately to adults with autism.

The statutory guidance (2015) states that Local Authority, NHS bodies and NHS Foundation Trusts should:

- Ensure autism awareness training is included within general equality and diversity training programmes for all staff working in health and care
- Ensure that all autism awareness training enables staff to identify potential signs of autism and understand how to make reasonable adjustments in their behaviour, communication and services
- Ensure that there is a comprehensive range of local autism training that meets National Institute for Health and Care Clinical Excellence (NICE) guidelines
- Ensure those in posts who have a direct impact on and make decisions about the lives of adults with autism (including, for example, psychiatrists, those conducting needs assessments) also have a demonstrable knowledge and skills in a number of areas including communication; how autism may present across the lifespan; common difficulties faced by people with autism; and the impact of autism on personal, social, educational and occupational functioning, and interaction with the social and physical environment
- Involve adults with autism, their families and carers and autism representative groups when commissioning or planning training.

Skills for Care, with Skills for Health and the National Autistic Society, has developed resources to help enhance awareness of autism and improve skills among social care and health workers; primarily the 'Autism skills and knowledge list'. This forms part of a range of on-line training resources available to all public services.

<http://www.skillsforcare.org.uk/Skills/Autism/Autism.aspx>

A detailed Training Code of Practice was developed and published in 2012 by the National Autistic Society in collaboration with a range of relevant organisations.

<http://www.autism.org.uk/working-with/training-and-experience.aspx>.

Currently KCC provides a basic awareness e-learning module to improve understanding of autism, and the Kent NHS CCGs ensure that all primary and secondary healthcare providers include autism training as part of their ongoing workforce development. The Royal College of General Practitioners (RCGP) also

has autism as a clinical priority for 2014-17, which should lead to improved awareness among GPs.

We recognise that there is a need to improve training on autism across the health and social care system. All those in health and social care settings should have at least a basic awareness of autism and understand how to adapt information in order to ensure good communication, understanding and engagement and understand how to make reasonable adjustments to environments.

We need to ensure that autism training is identified as a priority within local workforce development plans across relevant agencies and providers. These training plans need to identify priority staff groups for training and consider the training requirements for particular roles.

We will promote the provision and take up of autism training and awareness among other organisations, agencies and providers. We will encourage commissioners of training to ensure it is consistent with the SPELL framework. This includes engaging with commissioners to ensure provider agencies are appropriately trained.

We recognise that we need to involve people with autism, their families and carers in the design and delivery of training.

## **Best Practice**

### **Surrey's Autism Champions**

Surrey has brought together staff from health, social care, education, voluntary and private services onto a training scheme to develop Autism Champions. The staff involved perform a wide variety of roles in different settings. They receive autism training based on the National Autistic Society's SPELL framework which they are expected to cascade down to colleagues.

Each champion is given a mentor who supports them with their ongoing learning and who they can contact for advice and guidance. Staff are expected to incorporate their learning into direct work with people with autism and in making reasonable adjustments to local services. The scheme has been evaluated by the Tizard Centre, University of Kent and found to be very effective in raising knowledge and understanding and improving attitudes and practice.

## Best Practice

### Autism awareness training in Jersey

On the Island of Jersey, all staff in social service departments, as well as in the police, in youth groups and in most schools have been given at least basic autism awareness training, including awareness of the SPELL framework.

## Workforce development

- Training should be provided by, involve or at the very least have been developed with people with autism
- Training in basic awareness of autism is essential for all public service workers
- More in depth training is required for staff involved in the direct assessment, support and reviewing of those with autism and their families and carers.

9

## Core Strategic Objectives

	Objectives	Measures of Success
23	Ensure a range of levels training of training in autism is identified as a priority within local workforce development plans across relevant agencies and providers	Training needs identified in plans and staff of relevant agencies have increased knowledge and skills and are trained to an appropriate level
24	Work with other organisations and agencies, including those in educational settings, the criminal justice system, employment support services, and the voluntary sector, to promote the provision and take-up of autism awareness training among their staff training among their staff	All organisations have awareness training available to staff

## 16. The Criminal Justice System

### 'I' Statements (Think Autism)

*(I statement No. 13)*

- If I break the law, I want the criminal justice system to think about autism and to know how to work well with other services.

### Local People with Autism told us:

- People with autism have problems accessing understandable legal advice
- Police should have training in understanding the difficulties people with autism have
- The autism alert card sometimes helps
- People with difficulties should be better accommodated e.g. not left alone in a room too long, especially without adequate explanation
- There is a need for a list of autism friendly solicitors.

The National Autistic Society states on its website that a number of people with autism spectrum disorders (ASDs) are involved in the Criminal Justice System (CJS) as victims, witnesses or offenders.

There is no evidence of an association between ASD and criminal offending. In fact, due to the rigid way many people with ASD keep to rules and regulations, they are usually more law-abiding than the general population. The National Autistic Society states on its website that people with an ASD are more at risk as victims of crime rather than as offenders.

As the statutory guidance states when people with autism come into contact with the criminal justice system it is often up to them, or their carer, to explain what having autism means. In some cases, it can positively change the way that police or courts view a situation.

Autism understanding and awareness is key to ensure that people are identified and diverted to the most appropriate support. However in Kent there is no consistent training available to the criminal justice system; some training has been provided to



the police by various organisations including the local Autistic Spectrum Conditions Team.

A review of the all the referrals to the Autistic Spectrum Conditions Team since its inception, conducted in April 2015, showed that over 10% (49 Of 450) of all people referred were involved with or 'were on the edges' of being involved with criminal justice as perpetrators. Just under half of these people had been charged or convicted of a violent, sexual or drugs related offence. There is a need to improve access to appropriate preventive services for people with autism to prevent them being drawn into the criminal justice system.

Adults with autism in prison are now entitled to an assessment of needs and support from Local Authorities; the Kent ASC team has begun carrying out assessments in local prisons and commenced some training of prison staff.

We are committed to working with the Criminal Justice System (CJS) in Kent to improve their awareness and understanding of autism. We will extend the membership of the Collaborative to include key representatives and explore ways we can work together to improve the experience of adults within the CJS.

## **Best Practice**

### **The National Autistic Society's Criminal Justice Guide (2011)**

The National Autistic Society has produced a guide for criminal justice professionals (2005). It aims to assist all professionals working in the criminal justice system (CJS) who may come into contact with someone who has autism, particularly police officers, solicitors, barristers, magistrates, justices of the peace, the judiciary and the courts.

It is based on the experiences of people with autism and those who work with people on the autism spectrum. It explains why people with autism may become involved with the criminal justice system e.g. people with autism being duped into acting as unwitting accomplices in theft and robbery. It gives practical guidance for professionals for example in communicating with people with autism and how to adjust environments.

## Best Practice

### The National Autistic Society Autism alert cards

The National Autistic Society has produced Autism alert cards which can be carried by a person who has autism and used in situations where communication may be difficult. The alert card, developed in consultation with adults who have autism is designed to tell people about the condition and asks others to show respect and tolerance.

## Best Practice

### The Bedfordshire Think Autism Partnership Board and the Bedfordshire Criminal Justice System

The Criminal Justice System is well represented at the Think Autism Partnership Board meetings. Two developmental workshops have been held to consider how the CJS will contribute to the local strategy and as a result 'critical points' have been identified for autism screening, information sharing and autism training across the CJS. The CJS are now incorporating autism friendly ways of working, including training frontline staff in AQ10 testing.

## The Criminal Justice System

The National Autistic Society's position statement on the criminal justice system states:

- Some people with autism may be more vulnerable to criminal acts against them because of their social difficulties and they may be taken advantage of by unscrupulous individuals or become unwitting accomplices to criminal activity
- Once a person with autism is in the criminal justice system, the nature of their difficulties may not be recognised or may be misunderstood. In these circumstances it is possible for miscarriages of justice to occur
- Additionally there is a need for adapted community treatment programmes for people with autism who have offended

10

Core Strategic Objectives		
	Objectives	Measures of Success
25	To improve the experience of people with autism within the Criminal Justice System	People are treated equitably in the Criminal Justice System
26	To set up a task and finish group to identify gaps and issues for people with autism in the Criminal Justice System	Group report back to the collaborative with new objectives

## 17. Carers

<b>'I' Statements (Think Autism)</b>
<i>(I statement No. 10)</i> I want to know that my family can get help and support when they need it
<b>What Local People with Autism told us:</b>
<ul style="list-style-type: none"> <li>• There should be more training and activities available for carers and more financial assistance</li> </ul>

A carer is someone who in an unpaid capacity provides care or support to another person. Many people do not class themselves as carers: they are mums and dads, husbands, wives, partners, brothers, sisters, friends and neighbours.

In 2011, 151,777 people, or 10.4% of Kent's total population, provided unpaid care. This proportion is higher than the regional average of 8.9% and the national average of 10.2%.

Under the Care Act (2014), for the first time, carers are recognised in law in the same way as those they care for. The Act gives local authorities a responsibility to assess a carer's needs for support, where the carer appears to have such needs.

The Kent Carers Strategy sets out the vision to take forward the plan for carers, and organisations have been commissioned to provide support and services.

The Joint Strategic Needs Assessment (JSNA) 2013-14 outlines the challenges for carers by client group – older people, learning disability, dementia and mental health but there is no data on the experience of carers of people with autism.

The Autistic Spectrum Conditions Team provide information, advice and support to carers of young people and adults with autism and refers carers onto externally commissioned Carers Organisations for assessment and support. Some carers experience high levels of stress and difficulties dealing with challenging behaviours and families can be referred to the ASC in crisis and at ‘breaking point’.

Some families and carers need training and support on how to support the person they are caring for. Equally some family members are very well placed to provide training and support to others.

We will undertake further work to understand the particular needs of carers with autism and of those caring for people with autism.

<b>Core Strategic Objectives</b>		
	<b>Objectives</b>	<b>Measures of Success</b>
27	To identify the numbers and needs of carers with autism in Kent and the families and carers of those with autism and provide appropriate services and support in line with requirements of the Care Act	Carers with autism have equal access to support and services as carers without autism
28	Training is available and accessible for families and those who provide support for people with autism in an unpaid capacity	Families are accessing training and reporting it as useful

## 18. Autism Friendly' Communities and Conclusions

### 'I' Statements (Think Autism)

*(I statement No. 1)*

- I want to be accepted as who I am within my local community. I want people and organisations in my community to have opportunities to raise their awareness and acceptance of autism.

Think Autism (2014) states:

*“Autism should not be seen as an add on to services or work programmes, and with over 500,000 people on the autism spectrum in England, everyday services will already be seeing or in contact with many people who have autism. By thinking about and engaging with people who have autism more effectively, by making reasonable adjustments or adaptations and by involving them and building their capabilities, there will be better outcomes for them and a better use of public resources”.*

In Kent we are committed to building community capacity in line with the Government's Think Local Act Personal (TLAP) initiative:

- Building social support networks
- Encouraging membership of groups
- Nurturing an inclusive community
- Enabling everyone to make a contribution (participation and co-production)

Addressing these areas produces better outcomes for individuals and communities, in terms of better physical health, mental health and wellbeing as well as benefits beyond health and social care. There are other benefits include positive effects on crime and community safety, educational attainment, public sector efficiency, income, viability of local services and better neighbourhoods (Wilton, 2012).

One of the keys ways to make some of these things happen is by supporting people with autism to have a role in their local community – through work (paid or voluntary), through taking part in local and through using the same community facilities as others. This requires such facilities and events to be autism friendly.

Although everyone with autism is an individual, the SPELL framework gives us some relatively simple steps which can make a big difference to helping people with autism be more independent and more included. For example:

- Ensuring clear, unambiguous signposting, in particular for important places like toilets and exits
- Offering quiet waiting places
- Reducing unnecessary noise, smells, or overwhelming visual stimuli (e.g. very bright or flashing lights) in the environment
- Providing written information prior to an appointment.

This should start with public services and other places where people with autism are highly likely to have to visit relatively regularly e.g. GPs and hospital environments, banks, post-offices etc.

The fifteen 'I' statements that have been identified by people with autism, carers, professionals and others who work with people with autism in Think Autism (2014) are grouped into three themes: 1. An equal part of my local community, 2. The right support at the right time during my lifetime and 3. Developing my skills and independence and working to the best of my ability. The vision for this strategy is that if we achieve these core strategic objectives, Kent will be closer to having communities that understand, accept and support people with autism as set out in Think Autism (2014).

## **19. Appendix One - SPELL**

### **What is the SPELL framework?**

Over many years the NAS schools and services for adults have developed a framework for understanding and responding to the needs of children and adults on the autism spectrum. The framework is also useful in identifying underlying issues, reducing the disabling effects of the condition and providing a cornerstone for communication. It also forms the basis of all autism-specific staff training and an ethical basis for intervention. The acronym for this framework is SPELL. SPELL stands for Structure, Positive (approaches and expectations), Empathy, Low arousal, Links.

### **SPELL**

The SPELL framework recognises the individual and unique needs of each child and adult and emphasises that planning and intervention be organised on this basis. We believe that a number of interlinking themes are known to be of benefit to children and adults on the autism spectrum and that by building on strengths and reducing the disabling effects of the condition progress can be made in personal growth and development, the promotion of opportunity and as full a life as possible. They are:

#### **Structure**

The importance of structure has long been recognised. It makes the world a more predictable, accessible and safer place. Structure can aid personal autonomy and independence by reducing dependence (e.g. prompting) on others. The environment and processes are modified to ensure each individual knows what is going to happen and what is expected of them. This can also aid the development of flexibility by reducing dependence on rigid routines. Structure plays to the strengths of a sense of order and preference for visual organisation commonly associated with the autism spectrum.

#### **Positive (approaches and expectations)**

It is important that a programme of sensitive but persistent intervention is in place to engage the individual child or adult, minimise regression and discover and develop potential. In this respect it is important that expectations are high but realistic and based on careful assessment. This will include the strengths and individual needs of the person, their level of functioning and an assessment of the support they will need. We must seek to establish and reinforce self-confidence and self-esteem by building on natural strengths, interest and abilities.

It is vital that assessments are made from as wide a perspective as possible and that assumptions are made on the basis of painstaking assessment and not superficial enquiry. These should include a view of the barriers in accessing opportunity. For example, many people on the autism spectrum may have difficulty with oral communication, leading to an underestimation of their ability and potential.

Conversely some may have a good grasp of speech but this may mask a more serious level of disability.

Additionally, many people with autism may avoid new or potentially aversive experiences but through the medium of structure and positive, sensitive, supportive rehearsal can reduce their level of anxiety, learn to tolerate and accept such experiences and develop new horizons and skills.

## **Empathy**

It is essential to see the world from the standpoint of the child or adult on the autism spectrum. This is a key ingredient in the 'craft' of working with children and adults with autism. We must begin from the position or perspective of the individual and gather insights about how they see and experience their world, knowing what it is that motivates or interests them but importantly what may also frighten, preoccupy or otherwise distress them.

To make every effort to understand, respect and relate to the experience of the person with autism will underpin our attempts to develop communication and reduce anxiety. In this, the quality of the relationship between the person and supporter is of vital importance.

Effective supporters will be endowed with the personal attributes of calmness, predictability and good humour, empathy and an analytical disposition.

## **Low arousal**

The approaches and environment need to be calm and ordered in such a way so as to reduce anxiety and aid concentration. There should be as few distractions as possible. Some individuals may require additional time to process information, especially if this is auditory. They may have additional sensory processing difficulties; they may need extra time to process information or we will need to pay attention to potentially aversive or distracting stimuli, for example noise levels, colour schemes, odours, lighting and clutter. Information is given with clarity in the medium best suited to the individual with care taken not to overload or bombard.

Some individuals may be under responsive to sensory experiences and actually seek additional sensory sensations. Again this is best achieved with an approach where the input can be regulated.

Low arousal should not be confused with "no arousal". It is of course desirable that individuals are exposed to a wide range of experiences but that this is done in a planned and sensitive way. It is recognised that for the most part the individual may benefit most in a setting where sensory and other stimulation can be reduced or controlled. Additionally, supplementary relaxation and arousal reduction therapies, Snoezelen, music and massage, sensory diet etc. may be helpful in promoting calm and general well-being and in reducing anxiety.

## **Links**



Strong links between the various components of the person's life or therapeutic programme will promote and sustain essential consistency.

Open links and communication between people (e.g. parents and teachers) will provide a holistic approach and reduce the possibility of unhelpful misunderstanding or confusion or the adoption of fragmented, piecemeal approaches.

The person with autism, their parents or advocates are very much seen as partners in the therapeutic process. Links with the mainstream, through curriculum and other experiences, enable the individual to participate in a meaningful way in the life of the wider community.

The SPELL framework can be applied across the autism spectrum, including Asperger syndrome. It provides a context for and is complementary to other approaches, notably TEACCH (Treatment and Education of Autistic and related CommuniCation Handicapped children.)

From the NAS website accessed 29.02.16: <http://www.autism.org.uk/spell>



**Advocacy for All**  
bigger voices – better lives  
Speaking up Groups in Kent

## Consultation on the draft Integrated Strategy for Adults with Autism in Kent



October 2015

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## introduction

The **draft strategy for Adults with Autism in Kent** is a key piece of policy development in response to the national Think Autism Strategy. This follows on from the **Autism Act (2009)**, the first disability specific law designating statutory local government support and for Adults with autism. This group of individuals have received the least provision and support over the last 5 decades.

**Kent County Council** having set up the Kent Autistic Spectrum Conditions Team in 2014, have started to provide co-ordinated referral for diagnosis, social and employment support for such individuals. Improving service and outcomes for autistic adults is vital to enabling them fulfilling their potential. The strategy lays out the plan for services over the next 5 years.

Our task was to ask members of **Advocacy for All's Peer Support Groups** to give their **opinion** on the draft **strategy** and highlight the **important support needs** that will enable them to lead **valued lives** as part of the community.

## aims of the Kent ASC consultation

- to **ask** members for **feedback** of the draft strategy
- to **find** the **gaps** in support and services
- to find the most **important** areas of the strategy for people
- to **hear recommendations** to **improve** the strategy

## how we organised the consultation

We organised 2 consultation events across the county; one each for East Kent and West Kent members.

Members were invited to Maidstone on Saturday 17<sup>th</sup> October and Friday 23<sup>rd</sup> October in Canterbury.

Both events were centrally located in each region for ease of travel. Members were able to bring their carers or parents if necessary. 45 people attended the consultation, 39 of which were members.

The challenge of the consultation was to find autism - friendly environments that enabled the sensory needs of our members. We chose light and comfortable spaces that allowed free movement.

We delivered the meetings with the help of members using a powerpoint display and allowed for the discussion of key points of the strategy. People used post-it notes to record their views on what was currently working, what was not working and ideas to improve things in the future for each area.

Members were separated into 3 or 4 small groups and discussed important areas of the document for 20 minutes; notes from this feedback and personal experiences were taken.

After 1 ½ hours of discussion and time given to read the strategy; a specially devised questionnaire was given to attendees to discover their personal perspective.

Members who were unable or chose not to attend the meeting were offered the opportunity to complete the questionnaire and return within the deadline.

68 members received a questionnaire and a total of 39 questionnaires have been completed. Further results will be collated and shared with KCC.

## the questionnaire

A questionnaire was made to gather information about group member's opinion of the draft Integrated Strategy for Adults with Autism in Kent.

The first section is about what is most important for people within the strategy and if there are any gaps that the strategy does not address.



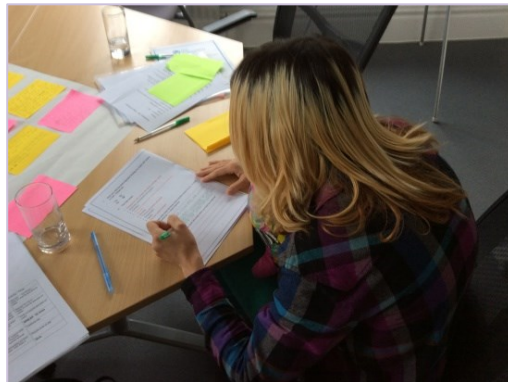
Then there is a section for each area identified in the strategy. Finally people can leave more general comments.

Every member was given the option of attending a consultation in either West or East Kent or filling in a questionnaire.

39 completed questionnaires have been received at the time of writing.

It was recognised that people would need to read the strategy to have an informed view before coming to a consultation meeting or filling in a questionnaire. People who were attending a meeting or filling in a questionnaire were given a copy of the strategy.

## the day



**Members were given time to read the strategy and express their opinion of services at different stages.**

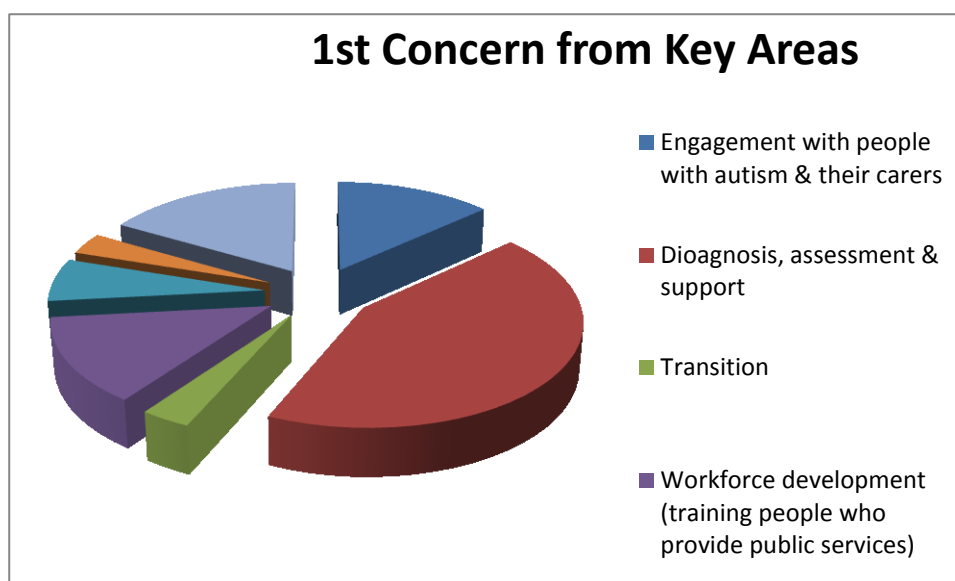


## findings

The **findings** from our participants were a **mixed view** of the current services and past experience throughout their lives. There were **recurrent themes** of **long periods waiting for diagnosis**, months or years without support and **women** being **misdiagnosed** with **psychiatric conditions** before autism was considered a cause.

The **lack of clear pathway** for diagnosis from GP level to varying social support and pressures of individuals to find employment show that there is someway before adults on the autism spectrum in Kent are given the integrated support best needed to **enhance their wellbeing**.

When asked the top 3 concerns from all key areas of the strategy **diagnosis** was the most important.



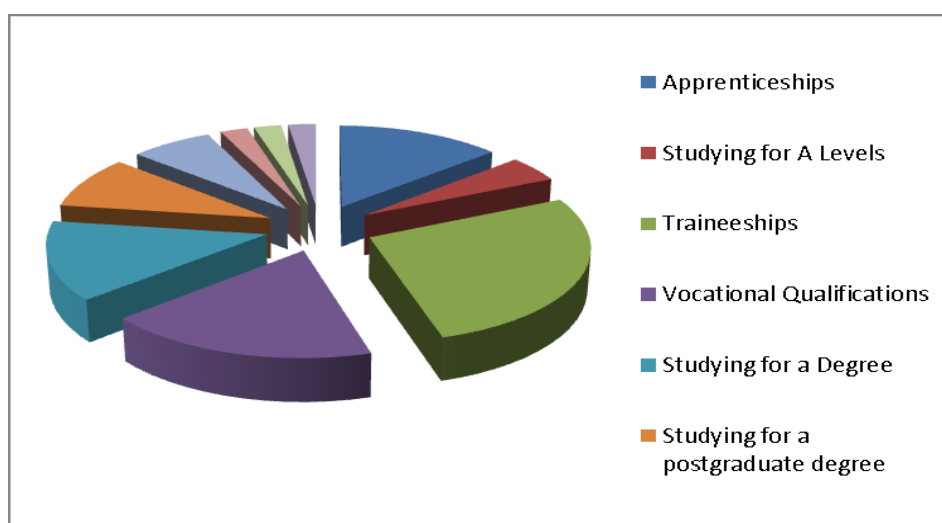
This was the area where most **negative personal experience**. Many had waited **at least 18 months** with no support or information during this time.

- next came **employment** as the 2<sup>nd</sup> main concern with members with 25% choosing it. Many were concerned at



their inability to find work and once in work there were issues around their condition that meant that they could not maintain employment. Many had been assessed as fit for work

- the 3rd main area of concern was **Workforce Development** with 25 % agreeing that training for employees that worked in public services was very much needed. It was felt that Council staff did not understand Autism itself and this lead to communication difficulties underestimating people's difficulties
- areas that members felt were missing from the strategy were **social skills training and training for medical personnel** so that Autism could be more recognised. This would minimise psychiatric misdiagnosis and excessive medical intervention
- members felt that structured placements or traineeships would benefit them most and help them **develop** their **unique skill sets**



## suggestions for the strategy

Here are the personal suggestions of members about key service areas.

**diagnosis:** ideas to improve this area

- support for people who are diagnosed as adults is fledgling and developing, needs a lot more development. Kent is quite advanced in having an ASC team but it needs resourcing. Its work is cutting edge
- psychiatrists and mental health nurses to be trained about autism and Asperger's
- any part of the plan should have 'continuous improvement' mechanism in place
- females are certainly still less widely diagnosed than males these days, what is being done to improve this situation?
- there are, to my mind, not any less females with an autism form diagnosis than males. It just manifests in a different way!
- new diagnostic method needed for women

**employment:** ideas to improve this area

- information should be supplied to employers about the skills possessed by people on the spectrum
- we need a structured transition plan while at school or university
- need better outlines on what reasonable adjustments employers should be expected to make
- communication agencies and an advice agency.

- college support and work preparation needed.
- PIP is too complex to navigate and skewed against ASC
- more training for staff
- autistic adults should not have to re-apply if they lose their job
- more willing employers and greater awareness in work environment

**workforce development:** ideas to improve this area

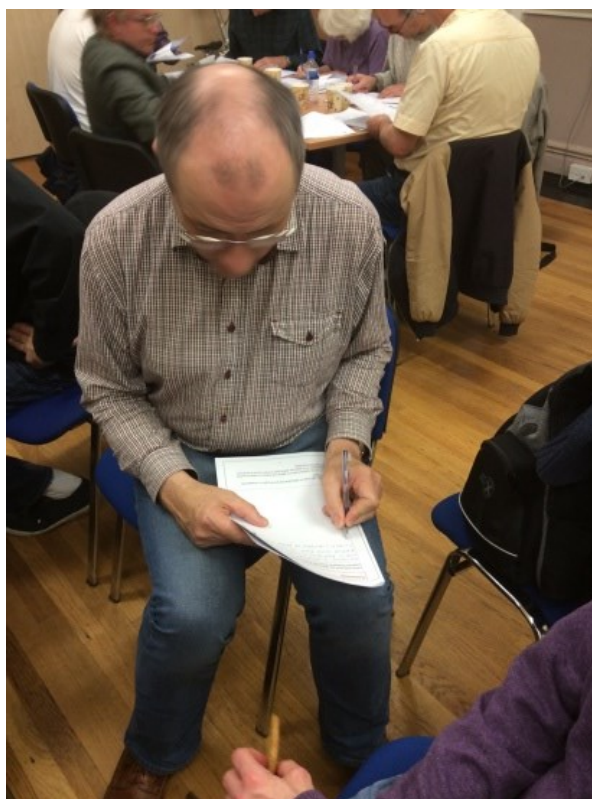
- consolidated list of services available
- training of hospital & service staff and hubs
- timetable for staff coming in – continuity
- build up positive relationships with medical staff
- shop staff to be aware
- environments: not aware of sensory issues: noise and light
- offering greater work opportunities by tapping into individual

## voices

Many members felt that this consultation must **not pay lip service** to their needs but be a real opportunity to tell KCC their experiences. No strategy can be formulated without knowing the common experience of the service user it aims to meet.

Some members felt a representative from Kent could have been present to really hear their perspective.

Members are keen to hear feedback on their views and how the strategy will be adapted further to reflect their needs and views of service.



## appendices

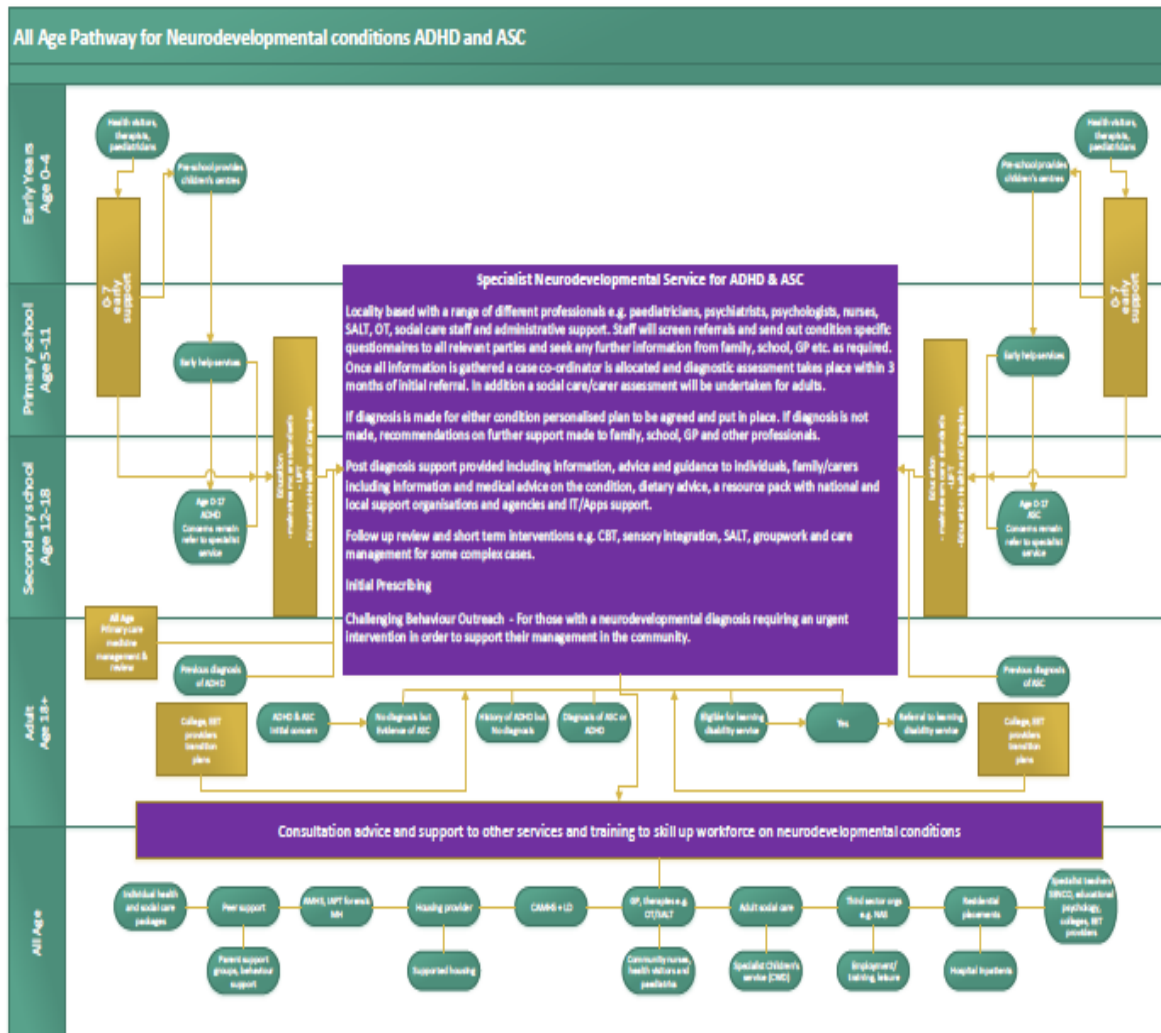


**bigger voices - better lives**

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Appendix 1	feedback notes
Appendix 2	questionnaire
Appendix 3	questionnaire results spreadsheet
Appendix 4	photographs

# 21. Appendix Three



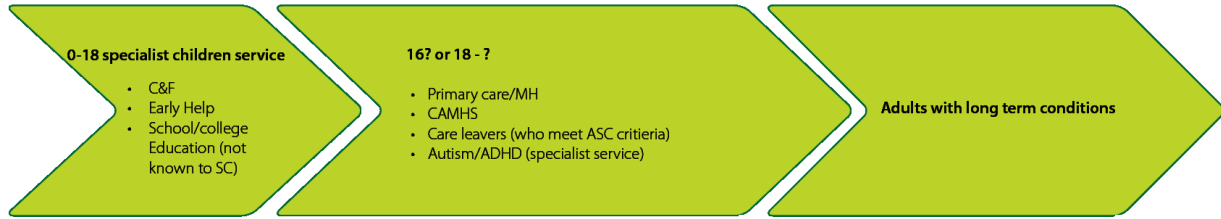
# 22. Appendix Four

Appendix 2 **DRAFT - CONFIDENTIAL**

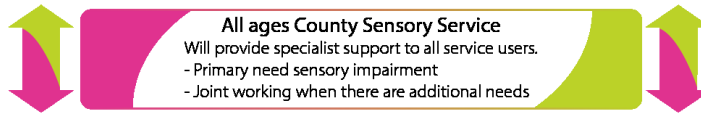
## Life span pathway

----- Assessment and review will be ongoing throughout the person's journey by all agencies involved -----

**Specialist service route**

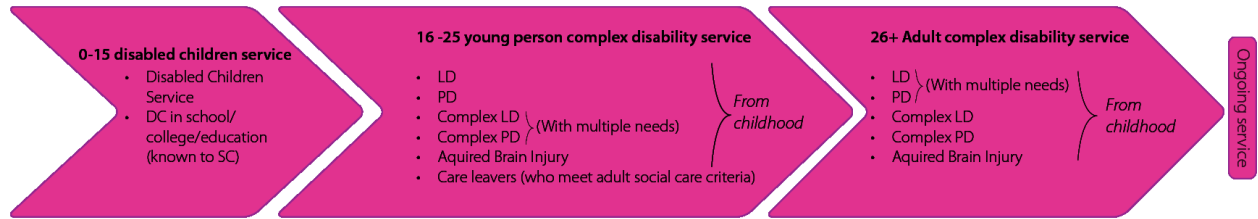


Can move between paths if support needs change



Can move between paths if support needs change

**Complex needs route**



----- Services to be wrapped around the pathway to deliver a smooth pathway for children, young people and adults -----

This pathway has been developed from information gathered from a number of different stakeholders and is for discussion

PSouthern (V2)

## 23. References and Links to other Strategies

Beadle-Brown, J., Richardson, L., Guest, C., Malovic, A., Bradshaw, J and Himmerich, J. (2014). Living in Fear: Better Outcomes for people with learning disabilities and autism: Main Report. Canterbury: Tizard Centre, University of Kent.  
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